



HELPING PEOPLE LIVE TO THE FULLEST



The Centers for Disease Control and Prevention (CDC) is dedicated to improving the health and safety of all people. It is CDC's driving principle that by developing and distributing accurate information, and by working with the strongest partners, that the health and safety of all people can be protected. That's why the National Center on Birth Defects and Developmental Disabilities (NCBDDD) was created in 2001.

The mission of this center is to promote the health of babies, children, and adults, and enhance the potential for full, productive living.

The work of NCBDDD includes:

- Identifying the causes of birth defects and developmental disabilities,
- Helping children to develop and reach their full potential, and
- Promoting health and well-being among people of all ages with disabilities.

CDC seeks to accomplish these goals through research, partnerships and prevention, and education programs.

FROM BEGINNING TO END, A BETTER LIFE FOR ALL

It might be the greatest wish all people have for themselves and their loved ones: a healthy, happy life. Often, when one's mind and body work perfectly, good health is taken for granted. Yet millions of people live every day with some form of disability, facing limitations in daily life activities. This includes infants and children with birth defects, genetic conditions, and developmental disabilities such as mental retardation, cerebral palsy, muscular dystrophy, and vision problems. These children might have challenges as they grow and learn about life, and often face more health problems as they grow older.

There are also increasing numbers of adults who lose some function, such as results from loss of a limb, loss of sight, or dealing with the onset of a chronic condition like arthritis.

The number of people living with birth defects, developmental disabilities, or acquired disabilities is rising and expected to increase over the next decade. With at least 54 million Americans currently experiencing a physical, cognitive, or sensory limitation, this is a serious health issue.



IDENTIFYING AND ADDRESSING THE CAUSES OF BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES



With better information, the Centers for Disease Control and Prevention can take better action. Currently, about 120,000 babies are born with a birth defect each year. More than 5,000 of these babies die in their first year of life—making birth defects the leading cause of infant mortality in the United States. About 17% of U.S. children younger than 18 years of age have a developmental disability. CDC and their partners can change these figures. The National Birth Defects Prevention Study, for example, involves 200 different research projects with states and research centers that address these and other important issues. With more information, the causes of these birth defects and developmental disabilities can be identified—and action can be taken to protect our children, and to develop new ways to help women have healthy babies.



- **Understanding Why Birth Defects Occur.** CDC is carrying out the largest case-control study ever conducted to find out why birth defects occur. The causes of about 70% of birth defects are unknown. Researchers will be able to study possible causes of both common and, for the first time ever, some very rare birth defects. Once the causes are identified, work can begin to prevent them.

- **Understanding Autism.** CDC is working hard to understand the frequency and causes of Autism Spectrum Disorders (ASDs). CDC is monitoring the frequency of ASDs in 18 states throughout the United States (via the Autism and Developmental Disabilities Monitoring Network) and is examining the potential causes of ASDs at six sites across the United States (Centers for Autism and Developmental Disabilities Research and Epidemiology). Both the monitoring activities and the etiologic studies represent the largest current efforts of this type in the United States. CDC also promotes sharing information to recognize the early signs of ASDs and to promote early screening for developmental concerns in all children. With this information, scientists, healthcare workers, educators, and parents will be able to better understand the conditions and help children reach their full potential.



CDC understands that even the best information cannot make a difference if the public cannot use this information to protect their own health. For that reason, another important role of CDC's National Center on Birth Defects and Developmental Disabilities is to reduce the risk of birth defects and developmental disabilities with known causes through education and outreach. This is done via public and health care provider education programs and partnerships at national, state, and local levels.

A few examples of the work in this area include:

- **Preventing Neural Tube Defects.** Neural tube defects (NTDs), including spina bifida and anencephaly, are serious, disabling birth defects of the spine and brain. Up to 70% of these birth defects can be prevented if women get enough of the B vitamin folic acid every day before and during pregnancy. CDC is working to educate women about the importance of consuming folic acid daily from supplements and fortified foods—even if not planning a pregnancy—through the media, health care partnerships, and community outreach.
- **Protecting Children From Alcohol-Related Birth Disorders.** Prenatal alcohol use can result in fetal alcohol syndrome (FAS), a leading cause of mental retardation and learning disabilities in children. CDC is working to prevent FAS by educating women to avoid alcohol if they are pregnant or might become pregnant, and developing effective counseling programs for women at highest risk. CDC is also educating health care professionals about how to recognize FAS in children, and working on new approaches to help children affected by prenatal alcohol exposure.





HELPING CHILDREN REACH THEIR FULL POTENTIAL

Much of the work at CDC's National Center on Birth Defects and Developmental Disabilities focuses on protecting people who are especially vulnerable to health risks—including children. The early years of life (birth to 5 years of age) are critical to a child's cognitive, social, and emotional development. CDC works with partners to develop public health tools and interventions that give all children the opportunity to maximize their potential health and well-being.



- **The Power of Parents.** The kind of interaction a child has with a parent during the first 5 years of life can set the stage for the child's entire life. Legacy for Children™ is an early intervention research study that focuses on the critical role of the parent in developing a child's overall well-being. Through this project, low-income mothers receive the support and fellowship of peers to work through challenges and make a positive impact in their children's future development.



- **Early Hearing Detection and Intervention.** Hearing loss is one of the most common birth defects, occurring in 1 to 3 of every 1,000 live-births, affecting up to 12,000 infants each year. When a child's hearing loss is identified soon after birth, families and professionals can make sure the child gets timely follow-up testing and intervention services at an early age. This will help the child to develop communication and language skills that will last a lifetime. CDC's Early Hearing Detection and Intervention Program (EHDI) works to ensure that all infants are screened for hearing loss before 1 month of age, all infants who do not pass the screening for hearing loss get a hearing evaluation before 3 months of age, and infants with a hearing loss receive intervention services before 6 months of age.



- **Improving Care for Families With Duchenne Muscular Dystrophy.** Duchenne muscular dystrophy (DMD) is a fatal condition of progressive muscle weakness affecting approximately 1 in 4,000 boys. CDC is working with partners to determine the prevalence of DMD, identify risk factors for secondary complications, assess the needs of families with DMD, and explore methods of earlier recognition and diagnosis of DMD. These efforts are intended to improve the lives of boys with DMD and their families.
- **Preventing Neurologic Damage from Jaundice.** Approximately 60% of full-term infants have jaundice. In most cases this is harmless. However, in some instances, if left untreated, severe jaundice can cause kernicterus, a type of brain damage that leads to cerebral palsy, hearing loss, vision and dental problems, and sometimes mental retardation. CDC is working with partners to promote early detection and effective treatment of severe jaundice before kernicterus occurs and is measuring how often kernicterus is diagnosed.
- **Understanding the Impact of Attention-Deficit/Hyperactivity Disorder in Communities.** Attention-deficit/hyperactivity disorder (ADHD) is one of the most common conditions of childhood. An understanding of ADHD and its impact on youth and families is needed to assist future prevention efforts. CDC is working with researchers to learn about the rates of ADHD and related conditions in communities, patterns of treatment, and the extent of functional problems and health risk behaviors among children and adolescents with this disorder.



PROMOTING HEALTH AND WELL-BEING AMONG ALL PEOPLE WITH DISABILITIES



Across CDC, programs are underway to ensure that people of all different abilities are able to live their lives to the fullest. Work in disability and health focuses on promoting the health of people with disabilities, and preventing complications or other health conditions secondary to a person's disability. In this effort, a wide range of programs, projects, and activities to maintain and improve the health and functioning of all people with disabilities are supported.

- **Empowering People With Disabilities.** CDC works with partners to study the health challenges faced by people with disabilities and to assist with better access to health care and overall wellness programs. One example is “Living Well With a Disability”, a program that empowers people with disabilities to take personal responsibility for their health by focusing on setting individual health goals such as physical activity, nutrition, and healthy communication skills.
- **Cancer Screening for Women With Disabilities.** Research shows that women with disabilities might be at greater risk for health problems than other women. They also face many barriers to health care, including getting regular screenings for early detection of breast and cervical cancer. Regular screenings will save potential physical, emotional, and financial costs both to the individual and to the health care system. CDC partners with states to provide accessible examination tables and equipment to ensure that these services are offered to all women.
- **Improving Living for People With Down Syndrome.** In the past 30 years, the lifespan of people with Down syndrome has increased significantly, but this gain differs among racial groups. In 1997, Whites with Down syndrome lived an average of 50 years, while African Americans lived only an average of 25 years. CDC is working to understand the causes of this difference, so that programs can be developed to improve the length and quality of life of all people with Down syndrome.



PROTECTING THE HEALTH OF PEOPLE WITH BLOOD DISORDERS

Blood disorders are complex conditions that can lead to chronic health problems. CDC is dedicated to addressing the health issues posed by these disorders on several levels by: identifying risk factors that can lead people to be at higher risk for health complications associated with having a blood disorder; enhancing the safety of blood products that are used to treat blood disorders; conducting education campaigns to raise awareness of blood disorders among consumers and health professionals; conducting laboratory studies to evaluate, improve, and standardize methods and procedures for classifying blood disorders; and working with partners to increase the effectiveness of treatments, reduce complications, and protect children and adults who have blood disorders.

- **The Unique Effect of Blood Disorders on Women's Health.** Bleeding and clotting disorders can pose unique problems for women related to the menstrual cycle and to the experience of pregnancy. These problems can include heavy menstrual bleeding (termed menorrhagia), as well as bleeding and clotting complications during pregnancy, and recurrent fetal loss. CDC is working to identify the causes and effects of bleeding disorders on women's health, and is working with health care networks to identify at-risk women and establish effective treatments.

Learn more about CDC's work in Birth Defects, Developmental Disabilities, and Disability and Health

www.cdc.gov/ncbddd

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